

1 April 1, 2014 Language Deprivation Syndrome by Sanjay Gulati, MD.

TIM: Hello, everyone. Wow. I'm thrilled to see such a wonderful turnout tonight. This presentation is being live streamed through the internet. For those who may be interested in watching the presentation. I am Tim. This is my name sign. I am a professor here at Brown. There's two different signs for Brown. One across the chest and one which is similar to the color brown. I am a professor of ASL and Deaf studies. We are thrilled to invite Dr. Sanjay Gulati here this evening.

He's a medical doctor at Cambridge health alliance. He's worked there over 20 years in the field of Deaf and Hard of Hearing services, both at Cambridge health and Boston Children's Hospital. I would like to welcome him here today. He is giving a presentation on a very important topic. That of language deprivation syndrome. It's abbreviated as LDS. We are thrilled to have him here. At some point during the presentation, there will be an opportunity for questions and answers. He will lecture for about an hour, at which point we invite you to come forward and make a line on the right side of the auditorium. We have a microphone here and interpreters. So you can sign or speak your question.

The reason we are having you line up this way is so that others in the audience who may be Deaf could see your questions clearly as you sign them. So without further ado, Dr. Gulati {APPLAUSE}

DR. GULATI: Thank you so much, everyone, for coming. I am happy to be here and discuss what I think is one of the most important issues in the Deaf world and in the Deaf community. I call it language deprivation syndrome.

My signs are not very fluent. I learned sign language at the age of 30. I was born with the ability to hear. I learned Hindi as my first language, English was my second. And those two languages I learned at the age of 1 to 3. So we call that my L 1 or my first language. I learned sign language at the age of 30. We call that the L 2 language, which is the language you learned later on in life.

Unfortunately, my voice also is not perfect at this time so I had to decide between signing or speaking and I decided to sign this presentation today. If you find that you can't understand my signs, please let me know.

You will notice the painting in the background. The artist is a woman who suffered from serious language deprivation. I posted this for two reasons. One, to remind myself and to remind all of us that language deprivation is truly atrocious. But also there can be a lot of joy. This artist was happy because she was able to move into a group home with Deaf people for the first time. She grew up in a family who loved her but there was no communication access. It was very frustrating for her, led to very severe behavioral difficulties. She was finally placed in a Deaf home and those behaviors did a 180 turn. She began to enjoy life and posted paintings. I wish I could tell you I had permission to show you this painting today. Unfortunately I do not. Her cognitive abilities don't give her the ability to grant permission. She doesn't understand that concept.

Looking at that painting, you will be able to see two things at once. The words and the pictures. By looking at the words and the pictures, you can see the signals with your eyes. The picture

was darker, the words being brighter, the signal would go down and the light noise would go up. Do you see what I'm saying? It's harder to distinguish the words within the painting. That's the signal to noise ratio. The issue of signal to noise ratio is complex.

There's many elements involved with language deprivation. I will try tonight to explain them to the best of my ability. I am not an expert. I am not an expert on the issue. It's very multidisciplinary. It involves the field of audiology, the medical field, perhaps surgery, politics as well, disability studies. There's more than one involved. Looking at this picture now is similar to that of someone who is Hard of Hearing. You can distinguish the signals within the noise. I was born fully capable of hearing. I lost my ability to hear later in life. I have become profoundly deaf. With hearing aids and lip reading and a lot of mental work, I am able to distinguish speech.

This is an audiogram. A very standard audiogram. I am going to show you the audio grams, what they really show and how it works and also hearing aids. This is the audiogram of what you would call a normal hearing child. This is based on what an average adult would hear. I place quotes around the word "normal" and I will explain why I did so later. Mild hearing loss. Moderate to profound. This was me 20 years ago. So if I was trying to talk to somebody, I could turn on my hearing aids. My range of hearing would go up on the spectrum. That way I could read lips and match the auditory input with what I was trying to figure out on someone's lips. Suppose someone would turn on the water faucet in the background, a person with normal hearing would be able to distinguish the difference between those two. Unfortunately with the hearing aids, the water sound and the speech was unintelligible. I could not hear either one clearly. My access to that communication was blocked. Hearing aids are not a solution to deafness. It only moves your input on the spectrum higher. The range is what's important. I just like showing an audiogram because it makes it seem like I believe that hearing is about sound and that's not what I believe. I believe that hearing is really about language. My definition of deafness is not about what you would see on an audiogram. My definition of deaf is a person who can't enjoy easy natural learned spoken primary language. Does that make sense? It's easy for people to be confused about that. Because some people like myself who were born hearing who are able to pick up spoken language and loss their hearing later in life, as opposed to somebody who was born deaf have completely different experiences.

If you look back in the history books and you read about oral education programs, they always give great credence to those who succeed in learning spoken language as their primary language. That's what they label as a success. But if you look at the number of those who succeed, 100 percent of the time are those who became late deafened. When they already had exposure to a spoken L 1 primary language. That person could then use whatever method they were exposed to. That method would then be beneficial for them because they had the L 1 language before they lost their hearing. Imagine a baby who is born. Baby's need things, right? A pregnant mother who uses alcohol will have a detrimental effect on the baby. Babies once born also need love. And if you are lucky, you will never see the picture from an awful experiment that was done several years ago with the monkeys who were taken from their mothers and left to their own devices. The monkey then has a choice. Wire mom with milk or a soft entity to be used as their mother without milk. Most of those monkeys clinged to the soft comforting object to the touch more so than the milk. If you leave a baby without a living mom, the baby will die. Interestingly enough, if a child is born blind without intervention or supports, the baby will show delayed development. Not only for visual aspects but motor skills as well. They won't roll over until the age of 1 year. Whereas sighted children will learn that skill at six

months. They won't walk until the age of 3. Whereas developmentally on target babies learn to walk at 1.

They use their vision to help them figure out how to navigate through the world. Most people don't expect that. With early interventions, a blind child can learn to develop on par with sighted children. Similarly if a child is born deaf, it's more serious. It's more like a child that's born without a parent than the child that's born blind. If they are nonsighted parents, this can lead to language deprivation syndrome. A child born with natural access to communication will be able to express its ideas. If a family does not have access to sign language in order to communicate with their child, most families develop what's called home signs. Maybe several hundred words that they attach to a sign. Home signs are not language.

What do I mean by a whole language, a complete language? It entails grammar and vocabulary. For me, grammar is how you put together words to develop meaning. Vocabulary is more like a database or a list of words. Some languages have a plethora of words. English has almost one million words. Some have not so many. All complete languages have grammar. And whether they have a long list of vocabulary words or a short list, grammar are equally complex. Imagine grammar like a machine. If a child has language deprivation, the machine is not able to be turned on. You may have heard the word grammar in school before. It's used to refer to the rules and ways of using words. That's not what I'm referring to here. What linguists mean when they say the word grammar -- have a look at this slide. All people use language. That may seem a little bit puzzling. Why isn't there more variety? Why don't all human languages have the exact kind of complex grammar, the same kind of complex grammar? People even with mental retardation can learn language, maybe, unless they have a severe language disability. Language acquisition should not be a problem. What this suggests is that human evolution -- humans evolve where language is very important. Without it, we could die. You need language to survive.

When you think of all people having language and then you look at the Deaf community, Deaf people are just fine. Deaf people have persevered in the human race, in the human community since time began. Hearing is not required for living. But language is required for living. And I want to make that distinction. I do have a story I'd like to share with you. This is my daughter. We call her Lucy. And this is at 1 and a half. She is 4 years old now, of course. We -- my wife, Lucy and I were together. We were visiting my wife's parents. And we got to my in-laws house and my daughter had a little stuffed animal. She named it Tasha. She was walking down some stairs and she forgot that she left Tasha on the stair. And oops. She stepped on Tasha and tripped and fell and actually hit her head pretty severely. I watched the whole thing. And of course, I was in shock. But you can't believe what she did next. She got really mad. And she stood up and she went right back up those stairs and grabbed Tasha and then she brought Tasha down to me and then she did this strangest thing. She held up her stuffed animal and she manipulated its arm. She made Tasha sign an apology. The next day -- after this whole thing was over. We were driving home. I was driving the car. My wife was looking at my daughter in the backseat. Lucy was signing to her. My wife was watching her sign. And my wife said, you know, Sanjay what is she saying? She's trying to tell me something about Tasha and her head and sorry. Those three words are the three words that she signed. Those three words were so powerful though. And let me tell you why.

There was so much information there. The fact that she had those words and the way she used those words were powerful. And to not have them would be tragically powerful as well. I will let you go ahead and read this slide.

Okay. Is it all right if I continue? I know this is an odd phrase, theory of mind. Some of you may never have heard of it. What that means is someone has a theory that other people out there have their own thoughts separate from themselves. That concept is really crucial for human beings. If you don't have a good theory of mind, it means you can't really empathize with other people. Imagine a child without language. Maybe a Deaf child born to a hearing family and they go on the same trip to visit the in-laws. And the child has a stuffed animal but it has no name. And something happens to the child. And the child comes to the parent with their stuffed animal. They come to the child to be soothed. But what's the experience for that child? It's probably traumatic. They're hurt. They do get soothed, definitely. But how much is missing? Imagine. That includes theory of mind. It doesn't happen for the child without language. So this is how I visualize language deprivation. And this happens to children without language exposure again and again throughout their lives. And that's a horrible experience. When I think of my daughter's experience and how she internalized that experience, I think about social and emotional lives of children. Socializing is so important for kids. Parents want their children to use their language because of the bond that that implies. And the connection to the family life, and the family values. And that's important. But what if the L 1 is delayed? That can be difficult to learn socialization. This is a fascinating study.

This is a cognitive scientist psychologist from Italy who compared two groups. Hearing kids who spoke Italian and then deaf kids who were bilingual and bicultural and compared them with mainstream children who had a little bit of spoken Italian and also some sign language. The researcher measured theory of mind in each of these groups and she was shocked by the results. And I'm happy to share them. This is -- there was an ENT that she was showing these results to. The idea is to help them and explain to them how L 1 is so important. The bibi Deaf child had very strong L 1 sign language of course, Italian sign language. The mainstream kids didn't, with cochlear implants, hearing aids and so forth, they were able to pick up words but their language was delayed. And the ones who had the best theory of mind were the Deaf kids. They were much better than the hearing kids even. So I feel badly for the last group of kids who are mainstreamed. Another important study in the Netherlands. Hearing kids were compared to kids with cochlear implants. The researchers themselves were shocked. No one expected this very strong conclusions. The kids with the implants seemed to have okay language. Not terrible. But the theory of mind was very delayed, not even close to kids with regular hearing. I like to call language vitamin L. Hearing, vitamin H, I don't think so. You don't need to be able to hear to have an L 1. L 1 is simply a normal first language. If you look at western history, there's a lot of thought about what would happen if you raised a child but you never talked to them. What would happen to that child? They even did some experiments. It was called the forbidden experiment because even the experimenters knew that it was wrong. It was allowed. It happened. In the 13th century, Frederick II said, yeah, I really do want to know what happens to a child who is not exposed to language. What if you didn't talk to the child? The theory -- what do you think the theory would be? That maybe the child would speak Hebrew. The child did not end up speaking Hebrew. However, the experiment worked. Because they ordered the -- the people were ordered to feed and care for the children but not speak to them. The children themselves ended up interacting with each other. Kissing, playing, and then the women joined in, the ones who were feeding them. And so that experiment showed that home signs do derive-- communication does derive from children to adult and vice versa. So

the experiment was actually a failure.

Language deprivation can happen with hearing people but not as often as it does to Deaf children, Deaf people. If you Google wikipedia and you look at language deprivation, you would find the same five names. There's Genie, there's Anna, there's a series of them. Casper. All of them are well known children who had language deprivation. This is -- you know, two or 300 years ago. Meaning that language deprivation in hearing people does happen maybe twice per century. Five kids in all that time. But in my clinic, I might see five people with language deprivation every single day. Again, if you look at wikipedia, they never talk about Deaf kids with language deprivation. Deaf people aren't even mentioned. We need to change that. Soon.

I'm trying to think of a good way to suggest critical learning period. So critical period for learning first language. 10 or 20 years ago we argued about that. But those arguments have more or less been settled. Now the researchers have been proving what happens in a brain. Rachel Mayberry has done a phenomenal research. She's an incredible person. She's been working on language and the brain for the last 30 years. Her most recent study uses F MRI. A scan of the brain but it's a special kind of scan that can see which part of the brain is working and which isn't. I'm sorry I have taken a little diversion. My apologies to the interpreters. People think -- where is language in the brain? Well the vision is in the back of the head, in the back of the brain. So if you are looking at something, it goes through your eye sockets and somewhere in the back of your brain. Of course it makes sense that sign language would be in the back of your brain, right? And spoken language is in the left temporal lobe. So that's interesting that sign language would be in a different part of the brain. But in fact, it is not. When you study people with natural fluency, native fluency in sign language and certainly that would not be me, the language is in the left temporal lobe in the same place that spoken language is located. Let's here. That is fast rapid processing. That is what happens in this part of the brain. Some native users of language when they see a word, they can't not read that word. It's automatic. You see a word, you read the word. It's subconscious. And that happens in the left temporal lobe. I struggle to read French, for example. Now I am very much aware of each and every word. I am aware of how the words look. I know how they feel. I can see the words. It's a visual thing. And my comprehension is less accurate. I confuse words. Had I grown-up in French, I wouldn't have that confusion. The words would be recognizable, automatically. So that is slow processing. It's more tactile. It's more visual, more motor than what happens in the temporal lobe. I'm signing -- I have been signing about 20 years. The signs probably move to slightly different parts of my temporal lobe. Whereas my French, that's moved as well. Because I have an L 1, that enables me to reach almost full fluency in another language. Had I not developed an L 1, I would never be able to develop any kind of fluency in any other language. Now Rachel is a very neutral, very scientific, ethical researcher. And this is something -- this is one statement that she came up with. And I quoted her exactly. I find it very compelling. If you don't have an L 1, you have brain damage. Why do people think signs were somewhere in the back of the head?

They were confusing it -- excuse me -- they were -- there is visual stimulation and that visual stimulation registers in the back of the head. But language is a whole different thing. It registers in the temporal lobe. Now in the very same lab, people were using more sophisticated tools that allows researchers to see where the brain is growing. It's fascinating. I love these results. I will let you read the slide and then I will explain it.

Okay. This is surprising. So in the back of the head, which we call the occipital cortex, or the occipital lobe, it's a part of your brain. People who are native signers had larger -- or an additional amount of gray matter in their occipital cortex. And that led people who are native fluent speakers -- it turns out they also have additional brain matter. It's people who don't have the L 1 that are missing that. So probably what this means is that kids who grow up with parents that name things. That's a chair. That's a book. And so forth. And that includes not only auditory but visual, those types of stimuli stimulate the occipital cortex. And it grows. Physically grows. Now later, if there's language deprivation, it can shrink. And if there's no stimulation whatsoever, it doesn't grow. When hearing parents want their deaf children to acquire their culture, they are thinking about language at the top of this list. Parents worry that kids won't be able to share their culture. But what parents don't understand, they can't be criticized for, you can't have that at the top of the list without the foundational steps below it. Language does make things —does many things to help people to process cognitively. There are languages that can be learned and easily forgotten. And it may seem like nothing, but it is something. Like I said, I am not a linguist or cognitive scientist or a politician. I am a clinician. What I've learned from language deprivation is from the patient who come to my practice. It's very common from what I have seen.

My Deaf and Hard of Hearing consumers want to see the research and what the connection is. And remember my story of Lucy, my daughter. She used words and it helped her so much to convey her ideas. And her fun experience with those three words, other children without access to those words would not be able to develop the empathy that she did. She would not be able to develop the theory of mind. And her lobes would not grow. With this deprivation you would expect a person to exhibit tantrums. And from this experience, we decided to measure it officially or formally.

We used 98 cases over a three month period. We measured at what age they were exposed to language. We measured how much of a danger they were to themselves and others. In my clinical practice, we've seen less than half of people fully developed fluency. Less than 10 percent have serious disfluency. So much for spoken language fluency. The green you see in this picture is normal fluency. Orange is less so. Red as you can imagine is not ideal. Many of our clients without proper early exposure to an L 1 find themselves in the severe category. So now using these statistics we look for connections. What we found is compelling. It's unfortunate. However, not surprising. Most adults with behavioral issues stem from frustration and lack of language and ability to express themselves. They can't empathize with others. They don't know or care how others are feeling. It's a cognitive issue. There are many Deaf people here who maybe have experience with some of these individuals who require a visual gestural mode of communication. They are unable to be a part of the Deaf community because of their language deprivation. They are unable to see multiple signs. So we have CDIs who specialize in communicating with those who are language deprived. Remember how I told you with hearing people that language deprivation happened five times within the last 300 years? And yet we see this every day in our Deaf population. So how can we use this information to help us fully identify whether or not we shouldn't plant cochlear implants or use hearing aids and how does this impact those? As a Deaf person who comes in contact with those who have suffered from language delay, you see a Deaf child with hearing parents contemplating implanting their child with a cochlear implant. They think it's the miracle cure sent from God. They think they can make a Deaf person become hearing. The problem with that is words are not an L 1. If you have the perspective of deafness that it needs to be cured, that it's a medical problem, then if a child were to speak a word any word, you would find that a success. We have others with the perspective that Deaf people can learn a signed language and become a minority language

user. They think a single word spoken is nothing to be celebratory over. Full, rich language is what you should be after.

The signal to noise ratio that I mentioned before, I just chose random results from cochlear implants and studies. It doesn't give you complete hearing. Those who have been implanted with a cochlear implant catch every third, fifth, or seventh word. And those people are celebrated because they have 70 percent access to language. Imagine these people were to read a newspaper and catch 70 percent of the contents. 70 percent is not enough. There are many issues there. And we will leave it at that. I'm sure there will be those who comment on their own experiences. I think this is pretty self-explanatory. It can help you visualize real language fluency. The problem is that Deaf people measure from the top-down. Whereas hearing people measure from the bottom up. Cochlear implant outcomes vary, just as in oral education varies. Some succeed, some don't. There's a lot of bias in this report. For example, I remember one graph that showed 57 kids who were cochlear implanted. It measured their language and showed a positive trend. So you would think you have to change your philosophy. But if you take a look at what the report was actually saying, each of those dots was a number. It started at 57 and ended up at the number 7. So where are the other 50 children? I read through the entire research and report. They never mentioned what happened to the other 50 children. I know where they ended up. They are in my practice, in residential therapeutic schools that cost \$400,000 a year. And once they graduate, they will then be sent to a group home. They have been implanted but they don't use the language because they don't have access to the language. If you take a closer look at the outcomes, you may see a different picture. Surgeons do the procedure. And they don't necessarily care what happens to the child as they grow up. Can you imagine a doctor doing a leg surgery on a patient and not caring whether or not that patient learns to walk again. So as we research, interview, collecting ideas we are in a working definition stage right now. And I do want to hear from you, people with lived experience. I want to hear what you think. And how you guys recognize language deficiency, language deprivation.

I would like to talk a minute about emotional response to disabilities. If you see someone with a disability, you have an empathetic reaction. For example, if you see someone in a wheelchair, that person in the wheelchair may be shocked by your empathetic reaction. And you may be a little shocked to see a person in a wheelchair. And the reason being is because you imagine yourself for just a split second what would happen to you if you were ever to be bound in a wheelchair. It's that sudden realization, that empathy that can be traumatizing and it's normal. It's a normal human reaction. But to that person in the wheelchair may or may not be feeling trauma. It may have been a traumatic event that led them to be bound to the wheelchair, but maybe not. Maybe that person just does not want to adapt. Maybe they are happy and content. Maybe that person is full filled by having people come up to them and ask them what happened to them. Or maybe that person doesn't want you to see the wheelchair, just to see the person. But you can't know that beforehand. And it's normal to feel unaware how to proceed. But it's important to distinguish a recent trauma from a chronic trauma.

What does it mean to label someone not normal? Is there a boundary where a normal person is inside the boundary and abnormal people are without that boundary? It's not so clear-cut. The ideal of normalcy comes from an arbitrary — so the idea of normal is basically you can think of it as on a curve. There's a curve of normalcy, a bell curve. If you think of western tradition, there have been different ideas about people with differences historically. And there is a vision that's called an ideal vision. Who is ideal? No one. We are all somewhere on different sides of the line. There is no ideal person. But we are all in the same circle. I think that's a better way of

categorizing human beings. Most hearing people think that hearing is normal. And who can prove that? I may have a different idea. Maybe I think that hearing exists within a range. Some people have more hearing than others. It's like some people are taller than others. Some people hear more than others. Some people hear less. And I think they are all normal. I can call them all normal, if I want to. That is a philosophy. It's a value issue. It's philosophical. It's a value issue. Maybe it's a medical issue. But I think I should stop now and give you some time for questions and discussion. If you don't mind lining up by the microphone if you have a question. And come on down. Don't be shy. I know you have some great ideas.

TIM: Okay. I will go ahead and start with the first question and I hope you all have some more questions and that we have a nice healthy line. Don't be shy. Really. This is an open forum.

This is what I would like to know. You said that, you know, if you -- let's say you have two hearing parents. And they have to make a decision about what to do with their Deaf child. And your best recommendation -- what would your best recommendation be?

DR. GULATI: Well, I would want to understand who they are. I would want to understand what are their fears? What are their concerns? What are their interests? In Massachusetts, I would need to know where they are from. Massachusetts has something like 358 towns. Each and every town is responsible for special education. Can you imagine the politics? Some provide sign language. Some towns provide cochlear implants. It's ridiculous. They don't so much think about the kids. But truthfully, each town has its own philosophy. So I would need to know that. And then I would open up the conversation. I would really be interested in their fears and their concerns. What are their feelings? It's normal to be a little shocked if you have a Deaf child and you are hearing. Sometimes when the parents meet a Deaf person, and I am a Deaf person. They calm right down. So we would have a conversation. And the conversation would go on for quite a while. It wouldn't be a short discussion. It would be a very long discussion. It's funny. You say if I meet a parent who have a newly born Deaf child. I continue to meet with parents regardless of the age of their child and quite often, they have 40 year old kids. I have 40 year old kids in my office and the parents are 60 and they come in and they are devastated. It really doesn't matter how old the child is. It has to do with the definition of success. And every parent may have a grading process that the child somehow doesn't meet their expectations. And it's normal.

TIM: Thank you.

AUDIENCE MEMBER: Hi. I am a student here. My question is in your medical training, you -- did you learn this information? Actually it's two questions. Where did you learn this information? My first question is about your training to become a doctor. Um -- and where you are working now, where did you get this information because it's so important. A lot of doctors -- well a lot of hearing parents, when they have a Deaf child they don't know what to do. So they ask the doctor. But a lot of doctors really don't have that expertise. They don't have advice to give. So it's such important information. So where can people get that information?

DR. GULATI: It's a great question. Really -- it's kind of shocking that -- the number of Deaf people that exist and yet how many hours in medical school do we spend studying it? I mean we study diseases for thousands and thousands of hours. But when it comes to learning about deafness, there's very little time spent. You need to learn from the perspective of Deaf people. And oftentimes all we learn about is hearing and the improvement of hearing. Some families will

have many, many surgeries and I understand that perspective. But I disagree with it. I think that you should try to improve -- you should try to change -- it's semantic. The idea again -- as I said earlier in my talk, it's cosmetic. I'm sorry to the interpreter. We try to make the person -- asking a hearing parent to learn a different language is a challenge. Imagine, let's say there's a new disease called French. French disease. {LAUGHTER}.

Okay. So what happens? Your child is born and they could learn French no problem and it would be the most natural thing in the world. But they would have difficulty learning English. Now what would you do? If your child was born with French disease? I think you would move to France or you would send your child to a bilingual bicultural school that used both French and English. There's a cochlear implant. And the child could learn some English, maybe not full English but some English. Maybe 25 percent fluency and 75 percent very difficult and not very fluent. Would you give up going to France or going to a bilingual program? I think that's part of the problem is the way people conceptualize it. They need to understand that ASL is a full and complete language. And that's what I teach -- when I teach in medical school, I make sure that Harvard medical students get this information. And oftentimes it's the first time they've ever heard it, which is sad.

AUDIENCE MEMBER: Hi.

DR. GULATI: How's your dog?

AUDIENCE MEMBER: Long story.

I agree with what you are talking about. LDS and how devastating it is. We -- when you think about language acquisition, some of my students have that. And as this becomes official, we really need to educate the hearing public, who's going to educate them. Some of their labels are really incorrect. And who diagnosed them?

DR. GULATI: That's my life goal is that DSM VI, actually have a diagnosis. In the last few years research has now become so solid. Before it was speculative. But now we have some clear results. If you don't have an L 1, you have brain damage. You cannot be resolved. And there's no more arguing. We've got evidence of this. So it will become a DSM diagnosis. We have the evidence. We didn't have it before. What can we do now? Well it's happening. Because we do need these diagnoses.

AUDIENCE MEMBER: Hi. I think I met you before, about 15 years ago. I was your client. Anyway, long time no see. I don't know if you remember me.

DR. GULATI: I am so sorry I don't.

AUDIENCE MEMBER: Well anyway, I was little. I was signing. And I went to the School for the Deaf. I was also mainstreamed. And it was a lot of talk about implants and I didn't want one. I thought I was fine without one. But I was interested in joining the military. I asked if I had a cochlear implant, could I join? And they said no. So I had to live with that. But I thought maybe for general communication, to be able to talk to hearing people, to do well in the hearing world, to go to job interviews. But you I don't know. It seems like it's not necessary -- it doesn't necessarily work that way. I think this is God's plan. And you just have to trust in God. And you don't need to have a lot of medical interventions that we are what we are.

DR. GULATI: I think that a disability in general is hard. Society labels what a disability is. So if all of the doors were short, all those who are taller than the door would feel disabled because it would be a struggle for them to get in.

AUDIENCE MEMBER: Yeah but you know, I am a chef. I have a lot of qualifications. I work in Cambridge. I am really a skilled individual. But I have difficulty with job interviews. I feel like people minimize my skills even though I am well trained. And I wonder if I should get a cochlear implant to somehow be more employable.

DR. GULATI: Well society is changing. It will allow you to engage without changing who you are.

AUDIENCE MEMBER: Right. But -- you know, when you go to the doctor, they always ask me if I want an implant. And it's like, I don't know why they keep asking me that. It's like -- I think they just want the money, to be honest.

DR. GULATI: Well some people do make a parallel. Sometimes it's harder —as a racial minority, for example, black people, it's harder to you know, get along in the culture in society. They feel that it's important for the system to learn to live with diversity through policy change. America has a very strong value on equality. And the Deaf community and Deaf culture makes a good argument for equality. And we are making our way there and just as you are here, we can talk to the many hearing people that are here. We have interpreters at our disposal.

AUDIENCE MEMBER: Right. But you know, it's not universal in the world. We have kind of a separate experience. I feel like we are a small group. The whole world doesn't understand us. I wish they would be more open minded. We need more national exposure.

DR. GULATI: And we wish the whole world was bilingual. I'm sure most of you are aware of Martha's Vineyard. Some know of it, some don't. It's a very interesting example. In the 1600s into the 1700s, people from England moved to America and they congregated on the island of Martha's Vineyard. There were people with the gene of deafness. They intermarried and had children and before you know it, a quarter of the population was Deaf. Everyone used sign language. The entire island was bilingual. And ASD, the American School for the Deaf, when it was set up had a high school satellite on Martha's Vineyard up to eighth grade. Deaf people were allowed to leave, go for a four-year education in high school and come back to the island. Deaf people have a better education than others at that time.

AUDIENCE MEMBER: Thank you I appreciate this discussion. I appreciate talking with you. I would love to talk to you again about this. We have a ways to go.

DR. GULATI: I'm very fortunate because for me sign language means I can continue to work in my discipline and I feel very fortunate to have enough respect to hear stories like yours. I'm humbled by that.

AUDIENCE MEMBER: Thank you very much.

AUDIENCE MEMBER: Hi. My name is Alex. I want to thank you for coming. This was a really great presentation. I have a question about -- you didn't really comment about reading. And reading and how that has to do with the L 1 or the development of the L 1. I was just thinking does reading at a young age help in any way?

DR. GULATI: As I said I am not an expert on literacy but there's different areas involved with reading. And my understanding is that people who read well early on must have some understanding of phonetics. And without that word to word connection doesn't make sense. On the other hand, if people have a strong L 1 with sign, when they approach school age their able to learn the English word for "cat" using the signed L 1 to explain the English word "cat." So they already have the concepts that have been developed with their L 1 that they can use to then scaffold them to learn English as their second language

AUDIENCE MEMBER: So it sound like you are saying you need an L 1 in order to acquire your L 2.

DR. GULATI: We have two studies that show those members of the Deaf community that have strong English literacy most of them have strong ASL skills.

AUDIENCE MEMBER: Come on people, we got to get some more people down here. Hi. I really appreciated many of your points tonight. Thank you so much for coming. And I am really interested in your publication. Is this published? Have you published this?

DR. GULATI: I will post this on the web. I will give the e-mail address to Mr. Richer and he can post it -- it's also on the key Cambridge health alliance with all the references that I mentioned.

AUDIENCE MEMBER: Great. Thank you.

DR. GULATI: Also the research is a pilot project, which we are working on. That will be published probably within the next two or three years. It takes time.

AUDIENCE MEMBER: Okay. Here's my question. I work with children and have been doing so for more than 20 years. Graduated from Gallaudet in 1990 and I worked at the learning center for six years in the bibiprogram and I have seen a huge change in the improvement in language in children and self-esteem. Then I moved to Rhode Island and my experiences here are different. I see less and less opportunity for kids to develop an L 1. What can we do? When the child is born, the parent, you know, you talk to people. They talk to other parents about what to do. So far what's been happening is in the general field, medical doctors who say they should let the parents decide on how to raise their child. But how can they make an informed decision? Parents can't make a decision -- I mean maybe they can make a decision about certain things. But most family members don't know anything about deafness. And so the access to that information is missing. We need to involve Deaf people, Deaf mentors. Also there needs to be good quality research to prove that educating the parents about L 1 for their children is critical. Maybe parents sign with their kids but there's not full language access because they are signing and talking at the same time. Many of the words are not actually signed. Or they will sign and then they will turn around and keep talking and the child has missed what they are actually saying. And in a family situation, the same thing happens. No one's perfect. But it's so important to show the families research so that they -- there's a better educated approach to change what's going on. And I guess my point is you were talking about L 1 and the language deprivation syndrome. And then the idea putting this in the DSM VI. How can we help these parents? And I'm sorry for the interpreters who are trying to figure out what I am saying as I am figuring it out. How can we get the word out so that more people understand language deprivation syndrome and when you have someone who is maybe

20 or 14 now, where they haven't gotten formal language, we want to get it to the little kids as soon as possible.

DR. GULATI: There's a wonderful book that I will add to the reference list as a post it. The book is about -- not about deafness, but it's about surgery on children with facial reconstruction. The author of the article is a woman. She had many paralleling issues. She had a facial deformity and her parents freaked out that she wasn't normal and her parents decided to go ahead with the surgery. She had 25 surgeries to change her face to make it appear more normal. But later in life, the woman looking back was thankful to her parents. But often they don't. The surgeon showed an awareness of the social aspects. The label of normal or abnormal. And I think that's an example, I hope, of the changes that can happen. There are other things involved. It's not only hearing. But identifying self-esteem and a sense of belonging. So what happened to this person was awful and children suffering language delays is equally terrible. But my hope is that we can do something about it.

AUDIENCE MEMBER: What you said about a child just saying one word and the parents getting so excited, versus a child being actually fluent in sign language, I mean, you know the evidence is there. It makes such a difference.

DR. GULATI: It doesn't mean I'm against cochlear implants. I want to make that clear. I am pro-L 1. There are some children who thrive with the cochlear implant and can develop spoken language and they do just fine. On the other hand there are many children that don't. And what I am focusing on are them.

AUDIENCE MEMBER: Hi. My name is Heather. I was born Deaf. And I work for an agency that provides home based services for Deaf and Hard of Hearing children and their families. The services are based in the home. And I see a wide range of things happening. There might be a third language in the home. There might be someone who signs. Another person who does English. Another person who uses Spanish. And there's one situation where there's a hearing parent that is trying to force their child to speak. But my question to you is this. With L 1, if they don't have -- you are saying it causes brain damage -- without one, you have brain damage. I mean, is there any chance for that child later on with a lot of exposure or is it a hopeless situation? Because should we just be looking at these children without an L 1 as having brain damage, and you know, I have questions about that and also about culture. The label is what concerns me.

DR. GULATI: One thing is that each person is probably different. Just like a plant. A plant requires water every day to nurture it to grow. If it doesn't have water it will die. Other plants, you can water once and not come back again for three weeks and water it again and the plant does just fine. And I think that's why you see such a gamut in the results from cochlear implantation. Some do very well. Some is doesn't work at all. We don't understand why that is. That's one issue that we face. And I lost my train of thought.

AUDIENCE MEMBER: Well I am getting to the idea of brain damage and any hope for that. How can we -- what can we do about that? I'm trying to make a judgment in my own mind about these families, the children who can't express themselves.

DR. GULATI: We don't know whether it's too late. So your experience with visual gestural communication, once that is their only mode of access to communication, that's when you would say it's too late. But as far as the critical time period, it's a straight line. And it's an average. And average doesn't mean it applies to everyone.

AUDIENCE MEMBER: Thank you.

DR. GULATI: Language development from six months -- a six months old child -- a hearing child can hear sounds, phone names that they can associate with language. And they can tell the difference from one language to the next. So normal language acquisition starts really the day you are born. And for Deaf kids, if they are diagnosed at age 1 or 2, it's too late already. If they are diagnosed as Deaf at age 3 or 4, it's tough. Age 5, it's really, really bad. So language is what it's all about.

AUDIENCE MEMBER: So here's my question. Is -- when is it too late? When do we give up? I mean -- I don't want to give up. I want to keep trying to develop these children.

DR. GULATI: Oh, you have to keep working at it and really immersion is the only way. It's what we call a language emergency. If a child has reached the age of four without appropriate exposure to an L 1. So if a child comes to the age of 4 and a half, we consider that a language emergency and we recommend complete emergents, 24-hour access to the language because the window is coming to a close. And it's interesting. I've seen many examples of kids at the age of 12, 13, 14, even 20 who are exposed to the language the first time who come here from other countries. And they can pick up a lot. But unfortunately they can't become fluent. They have an immense vocabulary. They can learn more vocabulary. But most of the time it's hard for them to progress. And be cognitive process. For example why something were to happen. So they can produce nouns and general ideas but they can't produce the expanded clarification of what it is they are meaning. They would expect you to fill in the gaps.

AUDIENCE MEMBER: Hi. My name is Michelle. And I am a school psychologist at the Rhode Island School for the Deaf. And I had a couple -- I have a comment and a question. My comment -- you were talking about early intervention and the national association of the Deaf and the council on education or management -- several organizations are getting involved with early intervention. A lot of specialists are involved on the early intervention team. We have to get people to come together and work collaboratively to be involved in the early education field. That's so important.

DR. GULATI: Thank you for mentioning that.

AUDIENCE MEMBER: And also I believe Gallaudet has a program called infant toddler family program. Where people actually learn about how to do that early intervention with Deaf and Hard of Hearing babies. But here's my question. We do get children at our school who come here from other countries or they may not communicate with their parents at home and they miss that critical language learning period. And people come to me and say, how can we help these kids? And it's just so hard to tell a parent that they've missed the opportunity. That the window is closed. And I don't know what to do to help them. It's hard for them to take state exams. It's hard for them ever to meet the standards that our state education system sets. It's hard to say to these parents, sorry, too late for your child. So how can you help me with this?

DR. GULATI: It's awful. I got to say. But sometimes it's what needs to be said. And remember the painting I showed at the beginning. That painting showed someone who had almost no language. About 100 signs, nouns. But they couldn't put them together to make a fluid story. And yet they could paint. So those were the language deprivation are still human. And we have to value everything about that person that we can. And I know for myself it's very important for that person to know who they are. And for them to know that they have language deprivation. At the age of about 14 or 15, you can start to do psychological testing and share those results with that individual. And you can explain to them that you know, you have a cognitive problem. And it will hurt and they will go through a period of grieving. But you have to help them understand who they are. So that they can know their strengths and their weaknesses. And help that person feel good about who they are. That yes, you have some weaknesses and a disability. But you can still find a way to live a happy fulfilling life.

AUDIENCE MEMBER: I agree with you. It's just tough because our diploma system depends on passing the state test. And that's a goal, we have to achieve certain reading levels. And I think our educational system doesn't understand that. And that system has failed these children. So it's a concern. You know?

DR. GULATI: It's getting worse because with the economy the way it is, they have a lot more emphasis on abstract thinking. And if you pass that critical period, then it's almost impossible for them to achieve that level of abstraction.

AUDIENCE MEMBER: I do like your research and I like that information because I think I could use that to show the parents what happens when the child misses that critical period. I think it's a good visual representation of what I can say to these parents and show these parents {APPLAUSE}. They are all from my school. And I am asking for their sakes as well as my sake. Thank you very much.

AUDIENCE MEMBER: Hi. I am Miko and I am a Brown student. I started learning ASL here, this year. Sorry that I'm still learning and I am still making some mistakes. I am wondering -- I am learning as a student. I do want to help people like me, born hearing but growing up with a hearing loss.

DR. GULATI: That's how I am.

AUDIENCE MEMBER: So my family wants me to study and be successful, of course. They think that hearing is -- needs to be fixed. That it's a medical problem. And I'm wondering how a student like me and like other students in my class could help other people if they don't -- if they are not doctors or scientists.

DR. GULATI: I think there are so many ways that you can help. And I think there are many ways -- many ways I am happy your parents visualized exactly what it would mean for you to be successful and maybe that visualization will come to fruition. And my parents wanted me to be a surgeon. But it really depends on how you feel. And it's important -- if hearing is important for you, then going through the experience of losing your hearing will be different than that of a person who is born Deaf. Just as if you were to compare someone who was born blind or who lost their vision later in life. So whether you are in a wheelchair or blind, Deaf people have the hardest time. And I think that Laurent Clarke -- I think what Heather said was that you have to --

Helen Keller said that blindness cuts you off from things but deafness cuts you off from people. I mean, the quality of relationships is what really matters. And I think it's your decision.

AUDIENCE MEMBER: So you are a doctor. If other people who are not doctors or scientists, what can we do to shift the culture? What can we do to make the cultural change?

DR. GULATI: It requires a multidisciplinary approach. And society needs to change. For example, I as a doctor, doesn't mean I can do everything. I can't -- I can go out and raise my flag and tell the world. But one person can't really make that much of a difference. It requires many types of people helping to helping the many. So if you e-mail me, we will talk more about that.

AUDIENCE MEMBER: Hi. My name is Sue. And I am not from Rhode Island. I am actually from Massachusetts. And I have been there for over 30 years. So I'm looking around and I see a lot of you from Rhode Island. But I'm from Massachusetts. And there was someone who made a comment, in the black with the bangs. I don't know your name. Martha. Okay. You were commenting about the learning center. And I thought, I was -- I was thinking about the teachers -- I am subbing at the Rhode Island School for the Deaf now and I am comparing that to the learning center. And I am noticing -- if I back up a little bit -- my daughter started at the learning center in the parent -- early parenthood program. She was born Deaf, of course. And she did everything at the right level. We were really forced to sort of deconstruct or decondition ourselves, deprogram ourselves what we had been taught all of our lives. And I really had to think about my own values. It was really hard for me. Because my parents are hearing. Of course, parents force their values on their children. That's what happens. And process then so different from the process I had with my own daughter. Anyway, my daughter was at the learning center. And she learned value systems that were good for Deaf kids. But we did have to come up with a mission statement at the learning center and it just having happened in Rhode Island yet. I do see struggles. It's a struggle I went through ten years ago where I taught at the learning center. But these facts are very good. So now for all of us in the community here in Rhode Island, we really need to work together with the Rhode Island School for the Deaf and other programs to look at our own values. Are we still with hearing people? Are we still with hearing culture? Can we change? And break away from that and value ourselves as Deaf people again. And be centered on our own deafness. I think maybe near Rhode Island it's time to get together. Deaf and hearing, parents and teachers, and have those hard discussions and talk about what we want for Deaf kids because where are they going to get their values? You know, my parents too. They always -- parents are such an important part of their child's lives. But we do have to have these honest conversations for the sake of the kids. I think that's what is needed here. It's happening in Massachusetts. It should happen here.

DR. GULATI: We have time for one more question.

AUDIENCE MEMBER: Hi. I may need your help. I am -- I am really bad.

INTERPRETER: It's okay, speak your questions.

AUDIENCE MEMBER: I am a student at BCC the reason I am here tonight's is I have an interest in education. I believe that all children from birth, Deaf and hearing should learn how to sign. Years ago, 10, 15 years ago I read an article. And I've had an interest in it. I grew up wanting to mow how to sign. I never knew anyone who was

Deaf and now here I am 57, trying to learn sign language. I am really bad. And it's a really long process. But I have an interest. I am really embarrassed because you just took up sign language this semester and you put me to shame -- look at you {LAUGHTER}. Um -- I had an interest for a lot of years to -- we have like a local cable access television in our town. And I would like to take parents who have infants and toddlers and children in the school system, have them all learn how to sign and then take students who are already in school system and make videos and put it out on a local public access television so the whole families will learn how to sign. Whether they have hearing or Deaf students. I really think that if we start it now, there will be a day that it won't matter whether you can hear or whether you can't. We will all be able to communicate bilingual in this country that is American sign language. And I kind of have thoughts on that. And I just wanted to say that.

DR. GULATI: It's interesting. But I think here in America, especially -- there's a lot of value placed on having one language, doing things one way. And we really -- we are thought of as a melting pot and everyone here speaks English. And that's a way that we can all talk with each other. But one of the reasons we are here is to dispel that. You know because that is based on audism. My dad -- in the world -- my dad speaks Pakistani and he actually has seven languages. There's really no limit to how many languages people can learn. In Cambridge we have one program for infants and they are taught 10 languages. Russian, German, they can learn them without any problems. So yes, sign language -- I often -- I would like to see that. You know, in New York, there are some very wealthy parents who have hired Deaf people for -- to teach sign language to their kids because sign is easier to learn. You can learn sign -- you can start picking it up at three months and there's a lot of benefits for kids. Deaf or hearing, to learn sign language. So a lot of people take advantage of that. At the same time we have surgeons saying, we are going to give the child an implant. Do not let them sign. They must learn English. And that -- we have these wealthy New Yorkers teaching their hearing kids to sign at three months. So -- you know, kids need options.

There are more than 800 studies that support this approach of learning sign. There are no studies that support the approach of having an implant but not having sign language. So you know, we talk. We use gestures. Everyone uses gestures. They are very natural. But why do we talk? It's almost definitely that sign language came before spoken language was even developed. Chimps separated from humans -- this was a study a while back -- they developed a couple of things that was special. One was dexterity. The ability to use fine motor movements with our hands. That's one thing that humans -- are distinct from chimps developed and through evolution. And a second thing is language. That's another thing that distinguishes us from chimps. Spoken language is not a given. The fact that people stood up, it just made their hands suddenly free so they could use them to sign. And also use tools and socialize with one another. So when people look back and you look at the development of the vocal cords, they came much later than dexterity in the fingers. We were probably signing well before we were speaking. And also the jaw and the evolution of the jaw, it was -- allowed us to call out in addition to sign. So this were many benefits. So you could talk in the dark. You could -- but sign has other benefits as well. For example, you can sign a great distance and somebody on the other side of the room can understand you. So -- you can warn people about on coming animals. So I do believe -- as I said earlier -- I think sign language came first and that explains why Deafness and seen language persist. We need more evidence of that and the whole idea of the vocal cord developing later. We actually have the evolutionary evidence of that. But who knows why. Maybe they didn't want people talking because they would choke. You couldn't talk and eat at the same time. But you can certainly sign and eat at the same time. So there could be whole

evolutionary story about this and the development of language. Sign has been around for as long as humans have been speaking. Okay. I think we should stop. I want to thank you all so much. It's been a pleasure to be here. And thank you for setting this up and thank you so much to our CART services, Jen, Carol, and Rebecca. And also our video people and our sound people. Thank you very much. {APPLAUSE}.

TIM: Thank you. This was fantastic. I really enjoyed it. It was very indepths and also very important. Now we could go on and have more dialogues and more discussion. There will be more publications, more research, and more activity in this field. We need to change the system. So I would like to thank you Dr. Gulati for being one of the movers and shakers in this community. I would like to let all of you know -- you might be a little bit hungry now. We do have some refreshments right outside the door in the hallway. So please make yourselves at home. We got plenty of goodies for you all. Thank you all so much {APPLAUSE}.